

December 2011-
January 2012
Southern Arizona
Post-Polio
Support Group
Est. 1985

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POLIOEPIC, INC.

There have been a lot of conversation recently about sharing some of the work of running 4 different support groups for polio survivors in Arizona. So many of us are reaching an age where it is harder for us to do the same things that we have, in the same way as before. There are 2 different groups in Arizona that each provide a newsletter, 2 different groups that provide a website, 2 different groups that provide resource directories and the list goes on. Would we gain or lose if we shared some of our outlets? Most of the conversation relates to: What would we have to gain by sharing? Well, we would gain more energy and time....however, the more important answer might be...to combine forces and create more of a "voice". Post Polio Health International understood that siren call years and years ago. They have tried to combine voices from ALL of the Polio Groups internationally, so they would have a stronger, louder and more powerful voice to those that don't know or understand about Post Polio Syndrome. What legacy are they going to leave to this world after we have gone? A lot more than the individual little different groups saying the same thing in the little old state of Arizona.

I know that members of each group (Polio Echo AND Polio Epic) do not want to lose what they already have, they don't want to become each other's group. That is understandable...however, do we take our toys and run home with them, or do we share? I am hoping that we will realize as discussions continue, that we can do more together than either one of us can alone. I don't want to disband, or merge. I want to grow, and create a new energy where we have the people with the strength in numbers to provide the services that we have and not wear down the one or two volunteers that do so much. We need to set the example of "conserve to preserve" in every way we can. Just my opinion, as these discussions continue. As a member of Polio Epic, you have the right (and I hope the strength) to ask questions. Each Board member listed in the newsletter WANTS to hear your opinions and questions. This is YOUR group, and we need to know what you think and what you want from YOUR support group. I am also reminded that our purpose of having a support group was to provide help, education and care for those that have survived Polio. I don't remember there being any distinction about what zip code they have on their mailing address. Call me "polly-anna", but I think there is a lot MORE we can do together.

Micki Minner

**General
Membership
Meetings
every
Second Saturday
10:00A.M.
Education Room
HealthSouth
Rehabilitation
Hospital
2650 N. Wyatt Rd
Tucson, AZ**

**December 10
Holiday Inn on
Palo Verde Road**

**Our Annual
Holiday
Celebration
Please make your
reservations now.
Flyer included.
Every year Polio
Epic celebrates
our members by
picking up half of
the cost of each
meal, just so we
can share the
celebration with
everyone!**

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Post-Polio Thoughts

Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska, (n.carter@cox.net)

CLOSE ENCOUNTERS OF THE POST-POLIO KIND

It's not as if we polio survivors never run into a glitch or two in a day. Let's face it—dealing with the unexpected has become part of everyone's routine. Developing the finesse to do that smoothly and successfully—well, that may be a different matter.

Consider Alice, a former nurse with serious arm weakness. Alice just returned home from two weeks at a rehab center where she was evaluated by a PT, an OT, and her personal physician, all of whom concluded that she needs a power chair.

Congestive heart failure and weakness in her legs make it difficult for Alice to walk around the house, and she finds it impossible to be independent when it comes to such things as getting to the bathroom. She needs the power chair.

So the rehab center folks contact a power chair supplier and arrange for them to meet with Alice to work out the details for finding the right chair.

Meantime, Alice (now home and renting a power chair) engages a home health agency to provide the PT her doctor orders. And herein lies the problem.

The PT, seeing Alice only once, decides he will be a miracle worker, says he'll have her up and walking in no time, and puts the kibosh on the power chair. Without consulting anyone, he calls the power chair outlet, switches them to his own questionable evaluation of Alice's condition, and declares that only a manual chair is indicated for our weak-armed Alice. Trouble ensues.

Time for Alice to jump into action.

We all have options. We do not have to sit passively and watch others take over our lives. This doesn't require shouting angrily in indignation, loudly stirring the pot with wild demands or accusations. A calm, quiet, "I'm in charge here," will do.

Alice could:

1. Start by firing the PT (if not the home health agency) and hire one that will honor the perfectly acceptable existing evaluations already attained. Check the qualifications of workers sent by any agency and be clear on job descriptions. Everyone must understand that our health care decisions are up to us—we do not casually hand over our authority to every individual who stumbles into the picture.
2. Speak up. If we have already been through a certain process and have no intention of doing it again, we have merely to say so. If someone insists on our participation when we know this to be wrong for us, we refuse. The word “NO” comes to mind. And if this is more than we can handle, then we’d best find ourselves a “NO-man” to carry along with us to utter the word.
3. Work with experts. For instance, see an assistive technology professional to get exactly the fit and the kind of chair needed. Don’t settle for anything less. Discover what works for us. Don’t allow a salesman with extra scooters in his inventory to decide that would make a better purchase than the chair we want. Who knows our bodies better than we do?

Of course it isn’t just Alice. Lots of people need to realize it’s OK to act on the courage of their convictions. You know how it is. Jack makes an appointment with his doctor. When he arrives at the office, he learns he will be seen by a nurse only. Fine, if that’s what he wants. If not, he needs to say so. Firmly, but calmly, he must insist a pinch-hitter is not acceptable. Next time he can avoid this situation by confirming this when calling to get on the schedule. Nothin’ to it.

Easy enough—no whining or complaining. We simply gather up our polio pluck and make our lives work for us. What could be better than that!

Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.

Source: Post-Polio Health International (www.post-polio.org)



FROM THE TREASURER...

*The beginning of our **2011-2012** fiscal year is here!. That means as of September 1, 2011 your dues will be applied for the 2011-**2012** fiscal year. CHECK the date on the address label; if it says **2011**, you are paid through August **2011**. If it says **2012** then you are paid up! If you receive your newsletter via e-mail, once a year, you will receive an e-mail telling you if you are PAST DUE.*

KEEP POLIO EPIC UP-TO-DATE:

- If you know you are moving, please contact us with your new address.
- If you are seasonal (snow birds), please remind us of your summer address let us know approximately when you are leaving and when you are due to return.

THIS WILL HELP POLIO EPIC KEEP OUR RECORDS UP-TO-DATE Contact Nannoe if you have any questions at **520-797-6898** or email her at Nannoe1@aol.com

DONATIONS: THANK YOU SO VERY MUCH

**Cece Axton*

**Gail Watts*

Sara Snyder

**Jacquie & David
Schmidle*

Lu Ann Pankratz

Arlene Wise

** Donation of \$100 or over*



IN MEMORY OF...

**LINDA FAILMEZGER – OCTOBER 2, 2011 –
FORMER BOARD MEMBER**

Polio Epic, Inc. and Literacy Volunteers of Tucson were privileged to have had Linda as a volunteer. Linda's special spirit lives on in the many lives that she touched. We have set up a special Linda Failmezger Memorial Fund to support her passion for adult literacy. Condolences to her family and many friends – Literacy Volunteers of Tucson.



Many Thanks!

Polio Epic and the Board want to recognize and thank the following organizations for supporting us and helping us make Polio Epic of Southern Arizona, the Support Group, for Post Polio, the success it is.

March of Dimes – helps fund a portion of our Newsletter.

DIRECT-Center for Independence - provides a room for our monthly Board meetings.

HealthSouth on Wyatt Rd. - provides a room for our monthly general meetings

Excerpted from the Arizona Center for Disability Law – Winter 2011 Newsletter

The City of Tucson continues to be out of compliance with federal disability laws and has been so for nearly four decades. A recent article in the Arizona Daily Star points to the fact that the City will need an estimated \$17 million to correct more than 2,800 problems. These problems were uncovered during a federal audit by the U.S. Department of Justice and subsequent self-audits of 150 buildings citywide.

According to Peri Jude Radecic, executive director of the Arizona Center for Disability Law, the City has disregarded the federal law and must do everything in its power to become compliant. The disability community in Tucson deserves full and complete access to City facilities.



“The fact that this issue has been studied and studied and little done to remedy the situation for 38 years points to poor management, deliberate indifference, and disrespect for the disability community. The Americans with Disabilities Act and the 1973 Rehabilitation Act were enacted by the people’s representatives to ensure equality of opportunity and independence. The City’s failure to comply is a violation of federal laws,” said Radecic.

The fact that changes to these facilities could have been made when the City had resources but failed to prioritize these fixes is

appalling and is no excuse for not moving forward. The Center will continue to monitor the situation in Tucson.

October 20, 2011, Polio Epic was invited to conduct a “geriatric Grand Rounds” at the University Medical Center, Advances in Aging, Lecture Series. The Arizona Geriatric Education Center also gave CEU credits to all of the attendees. Polio Epic has a “speaker’s bureau” to attend any conference, seminar, platform where we can talk about Post Polio. This was a great opportunity to educate doctors, nurses, social workers, and the public about Post Polio Syndrome. The following article from Post-Polio Health, which is an abstract of work done at the Karolinska Institute is one of the most important pieces of researching being done for Post Polio syndrome. It is the work that I have been asked about more than any other. I used this article to hand out at the lecture.

Cytokines are small secreted proteins which mediate and regulate immunity, inflammation and hematopoiesis (the development of blood cells).

“Time is the most valuable thing a man can spend”

Theophrastus (327bc-287bc)

Intravenous Immunoglobulin Treatment for Improving Muscle Strength

Kristian Borg, MD, PhD, Division of rehabilitation Medicine, Karolinska Institute, Danderyd University Hospital, Stockholm, Sweden, Kristian.borg@ki.se

Post Polio Syndrome, described as a weakness and atrophy in skeletal muscles, occurs when there is a failure in capacity of a nerve cell body to maintain large motor units. The large motor units are supported when the capacity for re-innervation is greater than denervation. Eventually this mechanism reaches an upper limit leading to muscle weakness. The cause of the denervation is unknown at the moment.

An ongoing inflammatory process in the central nervous systems of post polio patients has been described in some studies, but has not been found in other studies.

Our study in 2002 found an increase of cytokine production in the central nervous system of post polio patients. We know that:

- Cytokine levels are greater when there is an inflammation.
- Cytokine levels are higher in people with multiple sclerosis (MS), a known neuro-inflammatory disorder.
- The level of the increase in the post-polio patients was almost the same as in the MS patients.

We checked older studies to see what work had been done.

- Dinsmore reported an effect of prednisone in high doses and the effect eroded as the doses were lowered.
- Ann Bailey, MD at Warm Springs, Georgia in the early '80s, treated 80 patients with the oral vaccination, and 50 of those patients reported a positive effect on their symptoms. **Note: Using Oral polio vaccine to treat PPS is NOT an accepted practice.*

Due to her results and to the pattern of the cytokine increase, we began an open, uncontrolled study using intravenous immunoglobulin (Ivlg) in 16 post polio patients.

We were able to down modulate the cytokines, but what is the gain for the patient? We next developed a multi-center placebo-controlled study, double-blinded in 135 post-polio patients. (in the former study, we used 90 grams of Ivlg; 30 grams daily for 3 days). In this study, we used 30 grams for 3 days, repeated twice. We noted an increase of muscle strength of 4.3% in the post-polio patients. In the placebo group, muscle strength was decreased by 5.7%. This was statistically significant. The *natural course* of decrease in strength was 5.7% in one-half(½) year.

The benefit: Post-Polio patients selected for the study had an increase in cytokine levels, indicating inflammation in the central nervous system. The inflammation was down-modulated by the intravenous immunoglobulin (*Ivlg*) and down-modulated inflammation led to increased muscle strength and should result in a better quality of life.

DUES FORM

Name _____ Spouse/Partner _____ Date _____

Address _____ PHONE (_____) _____
 CITY _____ STATE _____ ZIP _____

If you wish to receive our newsletter via email: _____

PLEASE PRINT CLEARLY

_____ I am sending in my/our annual dues of \$10.00 per person for 2011-2012 fiscal year.

_____ I am sending my back dues of \$ _____

_____ I am sending in a *tax-deductible* donation in the amount of \$ _____.

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_____ I am UNABLE TO PAY dues at this time, but wish to continue my membership and receive the newsletter.

_____ Please remove my name from the mailing list. I no longer wish to receive the newsletter.

_____ Check here if you do not want your name, address, phone number and email listed in the
POLIO EPIC DIRECTORY

_____ I would like to be more involved in Polio Epic. Please contact me at the number above.

We welcome your comments and suggestions. Thank you!

Make checks payable to POLIO EPIC and return this form to: Polio Epic, P.O. Box 17556, Tucson, AZ 85731-7556

POLIO EPIC, INC



1985 - 2010

Wadleigh Grant

Could you use up to **\$500.00** to help get the Disability help items you need?

Polio Epic, Inc., is accepting applications within it's membership for a one-time grant of financial assistance. This program is made possible by a bequest Polio Epic received from Frank Wadleigh, a long time member and supporter of our efforts. The purpose of the program is to improve the quality of life for members, while supporting the overall mission of Polio Epic. Reasons for requests can be as varied as the members making them, all are seriously considered

Contact: Dave Marsh at 327-3252 or david-marsh74@yahoo.com